

Conceptualizing Post Intensive Care Syndrome in Children – The PICS-p Framework

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Abstract

Context: Over the past several decades, advances in pediatric critical care have saved many lives. As such, contemporary care has broadened its focus to also include minimizing morbidity. Post-Intensive Care Syndrome, also known as PICS, is a group of cognitive, physical and mental health impairments that commonly occur in patients after intensive care unit discharge. PICS has been well-conceptualized in the adult population but not in children.

Objective: To develop a conceptual framework describing Post-Intensive Care Syndrome in pediatrics (PICS-p) that includes aspects of the experience that are unique to children and their families.

Data Synthesis: The PICS-p framework highlights the importance of **baseline status**, organ system maturation, psychosocial development, the interdependence of family, and trajectories of health recovery that can potentially impact a child's life for decades.

Conclusion: PICS-p will help illuminate the phenomena of surviving childhood critical illness and guide outcomes measurement in the field. Empirical studies are now required to validate and refine this framework, and to subsequently develop a set of core outcomes for this population. With explication of PICS-p, the discipline of pediatric critical care will then be in a stronger position to map out recovery after pediatric critical illness and to evaluate interventions designed to mitigate risk for poor outcomes with the goal of optimizing child and family health.

Survival rates for children and adults who require intensive care for the treatment of life threatening illness or injury have dramatically improved worldwide. In both pediatric and adult critical care, decreased mortality has been accompanied by increased morbidity.[1, 2] This has resulted in a shift in the contemporary focus of the international critical care community from mortality reduction alone to the optimization of survivor outcomes.[3, 4] This broader focus on survivor outcomes has been propelled by a framework first proposed by Needham et al. that conceptualized the morbidities experienced by adult intensive care unit (ICU) survivors as Post Intensive Care Syndrome (PICS).[2] Since its publication in 2012, this framework has received significant attention from clinicians and researchers as a model for informing post-ICU services and testing interventions to improve PICS related outcomes. However, the direct applicability of the PICS framework to the pediatric ICU (PICU) population has not been established.

The PICS framework identifies potential impairments in three key domains: mental health; cognitive function; and physical outcomes for adult ICU survivors. PICS also recognizes that the family of survivors, namely spouses and adult children, often experience impairments in their mental health.[2, 5] Recognizing that the PICS framework may have implications for the pediatric intensive care population, an inter-professional group of international pediatric critical care health professionals with a common interest in PICU survivor outcomes assembled informally. Over the course of several months, the PICS framework was reviewed, discussed extensively in line with contemporary literature in the field, and subsequently re-envisioned for PICU survivors. This activity has resulted in the development of the Post Intensive Care

Syndrome – Pediatrics (PICS-p) framework (see Figure 1). The main aspects of this framework are outlined below.

Childhood - a Dynamic State

The core focus of the PICS-p framework is on the child. This is an intentionally broad term, used to describe infants, children, and adolescents typically cared for in the PICU setting. The heterogeneity of the pediatric population encompasses age and a wide spectrum of physiologic conditions occurring in children of varying social, cognitive and developmental capacities. In addition, an increasing proportion of these children suffer from chronic illnesses and developmental disabilities at baseline. Implicit in the PICS-p framework is the recognition that a child's critical illness occurs at a time of tremendous growth and maturation along a dynamic developmental trajectory. Consequently, PICS-p recognizes that a child's unique baseline status influences the eventual trajectory of their recovery. This, in turn, can impact the quality of the child's survival for decades.

The Family - an Interdependent Unit

The child survivor is invariably situated within and dependent on a family unit that varies in composition and dynamics and includes, but is not limited to, parents and siblings. The impact of a child's critical illness on family members may be profound as they, too, can experience psychosocial sequelae.[6] Family members' responses may, in turn, influence the outcomes of child survivors following pediatric critical illness.[7] The PICS-p framework integrates family outcomes within the pathway of child survivors to recognize potential interdependencies between individuals and the centrality of the family unit to the child.

Core but Interrelated Domains

Congruent with the PICS framework,[2] PICS-p can impact the child's physical, cognitive, and emotional health domains. Similar to adults, children can experience impaired health **at baseline, and experience further impairments** in relation to their critical illness as well as the life-saving interventions received in the PICU. Physical, cognitive, and emotional health consequences may occur in isolation or may interact with each other. PICU survivors are frequently discharged with impaired physical and cognitive functioning,[8] **which in turn may negatively impact their** emotional health. Of note, studies **typically assess** emotional health **indirectly using** measures of health related quality of life (HRQoL) which incorporate elements of physical health, functional status, behavior, and psychosocial health **rather than using mental health specific measures**. [9]

We add 'social health' as a fourth domain in PICS-p to acknowledge the burgeoning evidence that critical illness impacts the child's and family's social functioning [10-12] in relation to re-integration with peers; child and families' social capital; and the economic impact of unemployment on families when a caregiver has to give up work to care for a child. **Undoubtedly, family stress, resilience, and outcomes are intricately intertwined**. While not included in the PICS framework, we see social health as one of the core, interrelated domains of PICS-p.

Recovery

Experiencing critical illness and its attendant morbidities in childhood may expose survivors and their families to an extended pathway of recovery. **Currently** there is a paucity of longitudinal epidemiological studies (9,13) **with adequate control groups that consider the child's pre-PICU status and non-PICU hospital experience (10) in**

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describing the nature and duration of the child's post-PICU recovery. The proposed PICS-p model recognizes a multitude of recovery trajectories that vary according to the individual child and family. A comprehensive understanding of the natural history of PICU survival outcomes is lacking, but available evidence suggests that there is more heterogeneity in reported outcomes for PICS-p survivors and their families [7, 9] than for the adult ICU population and their spouses. Critical illness may impact a child's health status or alter the expected trajectory of illness in those with chronic conditions. Children's recovery trajectories may be domain specific, with more rapid recovery in one health domain than another but are also inevitably affected by developmental factors as the child matures and by the social and emotional impact on the family around them.

In summary, the proposed PICS-p framework represents an adaptation of the original PICS model to include aspects of the experience that are particularly relevant to the pediatric population. These unique features include the importance of baseline status, system maturation and psychosocial development, the interdependence of family, and trajectories of health recovery that can potentially impact a child's life for decades. The extent to which an intermittent PICU experience uniquely impacts the lives of chronically critically ill children also requires further exploration. Models, like PICS-p, may help illuminate the phenomena, stimulate discourse, and help guide outcomes measurement in the field. Empirical studies are now required to validate and refine this framework, and to subsequently develop a set of core outcomes for this population, as recently outlined for adult ICU survivors.[4] With explication, we will then be in a stronger position to map out the natural history of recovery after pediatric critical illness and to evaluate interventions

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designed to mitigate patient risk for poor outcomes. PICS-p focuses disciplinary attention on life after PICU care with the goal of optimizing child and family outcomes.

References

1. Pollack MM, Holubkov R, Funai T, et al: Pediatric intensive care outcomes: Development of new morbidities during pediatric critical care. *Pediatr Crit Care Med* 2014; 15(9):821-827.
2. Needham DM, Davidson J, Cohen H, et al: Improving long-term outcomes after discharge from intensive care unit: report from a stakeholders' conference. *Crit Care Med* 2012; 40(2):502-509.
3. Spragg RG, Bernard GR, Checkley W, et al: Beyond mortality: future clinical research in acute lung injury. *Am J Respir Crit Care Med* 2010; 181(10):1121-1127.
4. Turnbull AE, Rabiee A, Davis WE, et al: Outcome Measurement in ICU Survivorship Research From 1970 to 2013: A Scoping Review of 425 Publications. *Crit Care Med* 2016; 44(7):1267-1277.
5. Davidson JE, Jones C, Bienvenu OJ: Family response to critical illness: Postintensive care syndrome—family. *Crit Care Med* 2012; 40(2):618-624.
6. Nelson LP, Gold JI: Posttraumatic stress disorder in children and their parents following admission to the pediatric intensive care unit: A review. *Pediatr Crit Care Med* 2012; 13(3):338-347.
7. Colville G, Pierce C: Patterns of post-traumatic stress symptoms in families after paediatric intensive care. *Intensive Care Med* 2012; 38(9):1523-1531.
8. van Zelle L, Utens EM, de Wildt SN, et al: Analgesia-sedation in PICU and neurological outcome: a secondary analysis of long-term neuropsychological follow-up in meningococcal septic shock survivors. *Pediatr Crit Care Med* 2014; 15(3):189-196.
9. Ong C, Lee JH, Leow MK, et al: Functional Outcomes and Physical Impairments in Pediatric Critical Care Survivors: A Scoping Review. *Pediatr Crit Care Med* 2016; 17(5):e247-e259.
10. Rennick J, Dougherty G, Chambers C, et al: Children's psychological and behavioral responses following pediatric intensive care unit hospitalization: the caring intensively study. *BMC Pediatr* 2014; 14(1):276.
11. Colville GA, Pierce CM: Children's Self-Reported Quality of Life After Intensive Care Treatment. *Pediatr Crit Care Med* 2013; 14(2):e85-e92.

12. Manning JC, Hemingway P, Redsell SA: Stories of survival: Children's narratives of psychosocial wellbeing following paediatric critical illness or injury. *J Child Health Care* 2017:1-17.
13. Pinto NP, Rhinesmith EW, Kim TY, et al: Long-Term Function After Pediatric Critical Illness: Results From the Survivor Outcomes Study. *Pediatr Crit Care Med* 2017; 18(3):e122-e130.

Legend: Figure 1. Post Intensive Care Syndrome – Pediatrics (PICS-p) Framework.

The critically-ill child, the focus of our attention, presents to the PICU exhibiting varying levels of health at baseline. The child experiences the PICU within their family unit that includes parents and often siblings. All experience the PICU and require consideration at the family, parent, and sibling level. On PICU discharge, the physical, cognitive, emotional and social health of the child varies and is influenced by the child's pre-PICU state, development, and maturation as well as the natural course of a child's underlying illness. Family, parent, and siblings' emotional and social health may also be affected. The trajectory (y axis) and duration (x axis) of recovery is variable and may improve, deteriorate, vacillate or remain static over days or decades.

